Neurosciences: Specialised Neurology (Adult) Service Specification: Engagement Report

22 April 2025, Version 1

Topic details

Programme of Care	Trauma
Clinical Reference Group	Neurology
Unique Reference Number (URN)	D04/S/a - 250801

1. Summary

This report summarises the feedback NHS England received from stakeholder testing, as part of the engagement process during the update of the Neurosciences: Specialised Neurology (Adult) Service Specification.

2. Background

The service specification for Neurosciences: Specialised Neurology (Adult) has been updated following the Full Methods Process. The review was led by the Chair of the Neurology Clinical Reference Group (CRG) and the Lead Commissioner for the service and supported by a Specification Working Group (SWG). Membership of the SWG included Clinical members, Lead Commissioner, Public Health, Patient and Public Voice (PPV), Neurological Alliance, Getting It Right First Time (GIRFT), Royal Colleges e.g. Association of British Neurologists (ABN), Royal College of Psychiatrists, and the British Society for Clinical Neurophysiology. Co-opted members i.e. finance, quality and nursing, information and intelligence were also key members of the group.

3. Feedback analysis

3.1 Stakeholder Testing

The service specification was sent for stakeholder testing from 3rd January 2025 until 3rd February 2025. Sixty-five responses were received, 45 were on behalf of organisations and nineteen from individuals. A breakdown of the responses for each question is set out below.

3.1.1 Summary of participants

2. Are you replying on behalf of an organisation?

More details

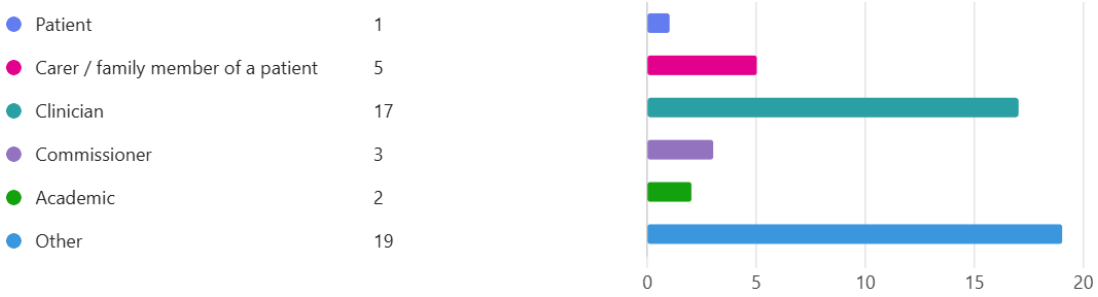
Remit of Organisations:

16 respondents (36%) answered support for this question.

Individual respondent characteristics:

5. I am responding as an individual

More details



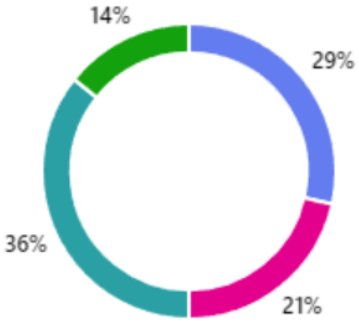
3.1.2 Responses to questions on service specification changes

- The specification outlines an integrated neurology model and the pathways and aspirations of an integrated neurology system. Through this model patients should

have access to care and treatment closer to home and more fluid transition in and out of specialised neurology services.

To what extent do you agree that the pathways of care are clear?

Strongly agree	4
Agree	3
Neutral	5
Disagree	0
Strongly disagree	2



- Additional comments to support previous response.

"It was positive to see the emphasis on a good transition from children to adult services, and care/treatment closer to home."

"it is encouraging to see mental health support recognised as essential throughout the pathways"

"In order to provide more clarity, it would be useful to be specific on the exact definitions of what is meant by general neurology and core neurology. 2. When assessing the equitable access to all commissioned specialised treatments for neurological conditions, what will be the criteria, how often will this be reviewed and how will any improvements in their access be decided? In other therapy areas such as lung cancer, specific roles have been created to monitor and give feedback to the NHS on pathway metrics. 3. Non-NHS organisations and individuals are unable to access the NHS England Neurology ICB Dashboard. To improve transparency, communication and understanding, could the dashboard be made public?"

"Comprehensive on organising principles of services across all categories of neurology services/within Integrated Neurology Systems with appropriate local flexibility on precise delivery infrastructure"

"I think the focus on improving population health via integrated neuro services is good, and having it laid out explicitly through the specific model will be useful in advocating that"

"Perhaps there should be a stronger focus on comorbidities in adult learning disability services. These are more considered in paediatric services. For example better crossover between services for conditions like ADHD and autism"

3.1.3

Do you foresee any challenges in implementing the revised specification?

- Additional comments to support previous response.

Workforce issues - do you have the staff to carry out what is required in the specification?

'This specification provides an ambitious framework for more accessible integrated neurology services. We see two main challenges to implementing the revised specification: the workforce shortages facing neurological services and a shift in working culture in some elements of the healthcare system towards a more collaborative and integrated approach. However, these challenges should not delay or prevent the finalisation and implementation of the revised specification, which is welcome. The forthcoming 10 Year Health Plan and the refresh to the NHS Long Term Workforce Plan also present important opportunities to address the neurology workforce challenges and provide sufficient resource to ensure the standards set out in this specification can be implemented to best effect'

"More support is needed at ICB level to understand the specification and patient flows"

"A key challenge will be that while the specification mandates clear guidance from ICBs, the specifics of service delivery will vary across different Integrated Care Systems. What appears as a well-defined pathway in one area may not be replicated elsewhere, leading to potential inconsistencies in access and quality of care. The requirement for collaboration across multi-ICB geographies to secure service provision where there is no local provision may also present difficulties, as differing priorities and funding models could hinder the establishment of consistent pathways for neuropsychiatry and neuropsychology support. The need to integrate specialised mental health services with general neurology services, while also ensuring that consultation-liaison teams in non-specialised settings have access to specialist mental health expertise, might strain existing resources and require significant structural and cultural changes within healthcare providers"

The revised service specification provides a more comprehensive model of care, detailing the requirements for specialised neurology services. It also outlines the expectations of non-

specialised neurology services, with an emphasis on a system-wide approach, for example, when ICBs are commissioning neurology services. An Annex has been included which details the proposed Minimum Service Levels for a range of conditions. Below are responses and comments with regards to each of the conditions outlined in the Annex.

Do you have any comments on the addition of Functional Neurological Disorders (FND) and complex headache to the service specification?

'The addition of Functional Neurological Disorders is very welcome as it is the second most diagnosed condition in neurology'

'Important to include this, however in practice - the pathways for patients with FND are limited'

'I think this is an excellent idea. FND and headache are the commonest conditions we see in neurology and recognising that through the service spec is excellent. Delineating what should be provided in each part of a neurology service is very useful'

Do you have any comments on the proposed Minimum Service Levels for Epilepsy services?

'I have little to suggest it reads well to me and I feel covers what we need for our patients in terms of neurology though little has changed and does not necessarily need to. The expectations of services for epilepsy was very good particularly around neuropsychiatry and neuropsychology'

'Clear, pragmatic and includes reasonable expectations for local services and Neurology Specialist Centres. However, may be perceived as aspirational in some areas of the country'

This section should mention services for patients with functional seizures, referencing the FND section of the service specification. We feel the document needs to make clearer that there are many types of complex patients in epilepsy who may need access to more complex care (not only those on surgical pathways). This might include patients with complex communication needs, pre-conception and pregnancy advice, very refractory epilepsy, patients with complex comorbidities (e.g both epilepsy and functional seizures) In specialist neurology centres, video EEG telemetry services should include inpatient provision for patients who need drug reduction or cannot manage a home set up.

Do you have any comments on the proposed Minimum Service Levels for Movement Disorder services?

Effective integration with local Geriatric medicine services is important so that patients can receive appropriate bespoke care. This should be defined by frailty/need rather than age

Good. Additional funding likely to be required to support cross provider collaboration incl additional CNS/ACP (esp community based for those most complex and to support primary care) and access to community neuro therapy can be challenging

Clear, pragmatic and includes reasonable expectations for local services and Neurology Specialist Centres

I would suggest altering the wording around End of Life care within minimum service specification for ICS provision in secondary care. A focus on End of Life care only, neglects the important benefits for PwP and carers of integrated palliative care (implies an earlier involvement without just a focus on EoL care) as evidenced in RCT (Kluger et al)

Do you have any comments on the proposed Minimum Service Levels for MS & CNS Neuroinflammation services?

Clear, pragmatic and includes reasonable expectations for local services and Neurology Specialist Centres

Overall, the MS &CNS Neuroinflammation services included in Annex A 2 are very thorough; there are a couple areas that would benefit from being added. GP referral Firstly, there is no mention of timeline for GP referral into a specialised neurology service. Despite the service being focused on secondary care, this is how patients would enter the services and where the backlog is so therefore would be an important addition.

Do you have any comments on the proposed Minimum Service Levels for Neuromuscular Disorders services?

These are very much welcomed. They are rather generic, and hope they will provide a catch all service. However, we can't see any gaps. Our only comment is with regard to outcome measurement and success criteria. How will Trusts be judged on whether they meet each layer of need, and how will outcomes be rewarded or admonished, and performance judged. This is part of a contract after all.

We welcome the emphasis on comprehensive specialist MDT involvement, aligning with NICE guidelines and the Optimal Clinical Pathway for MND, as well as the prioritisation of access to respiratory, gastroenterology, and palliative care services. Rapid review pathways and collaboration with community services are also important for timely, localised care. Encouragingly, research participation, clinical trials, and genetic testing are integrated within the specification, but a lack of investment into the workforce may hinder equitable access and implementation.

The minimum service levels also do not currently reference maternity services, given the importance of better collaboration between specialised services and maternity services to achieve the best pregnancy outcomes in women with neuromuscular conditions.

Do you have any comments on the proposed Minimum Service Levels for Cognitive Neurology services?

Effective integration with local Geriatric medicine and old age psychiatry services is important so that patients can receive appropriate bespoke care. This should be defined by frailty/need rather than age.

Clear, pragmatic and includes reasonable expectations for local services and Neurology Specialist Centres

Do you have any comments on the proposed Minimum Service Levels for Functional Neurological Disorders services?

There is a lack of clarity on the interfaces between local mental health teams and the specialist expertise mentioned in the Minimum service level. We are likely to encounter resistance to engagement from overstretched local mental health services who have historically been reluctant to engage with "organic" mental disorder. There is little understanding of Functional Disorders, even among mental health professionals. Without a significant and concerted effort to engage, educate and upskill the workforce we may find that this target is unrealistic.

Clear, pragmatic and includes reasonable expectations for local services and Neurology Specialist Centres.

Do you have any comments on the proposed Minimum Service Levels for complex headache services?

It is unclear who has responsibility for primary headache disorders between Primary and Secondary care in my opinion. All migraine should be primary care led care with some specialist advice from secondary care

These are very good - very welcome having such clear separation of core vs specialised service expectations - our DGH headache capability follows this to some extent but we are reviewing this and I will use the proposed minimum service levels as an explicit guide going forward

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resistance to engagement from overstretched local mental health services who have historically been reluctant to engage with "organic" mental disorder.

Please provide any additional comments that you would like to make about the revised service specification (in under 500 words)

Really clear and well thought out service spec. It is good to see an emphasis on transition services, community services and on support from neuropsychology and neuropsychiatry

The revised specification does appear to be well thought out (with the caveat that I am a parent carer and not an expert in the planning and delivery of services). It feels like it would provide an excellent care to patients, but I do have a concern around the ability to deliver everything within the specification due to funding and lack of workforce.

I found it extremely easy to read and understand and I feel it outlines well the standards required by the NHS.

Overarching feeling is that it is comprehensive (if long!). Very welcome that this recognises that most neurology is happening outside regional neuroscience centres and addresses in DGHs. A positive vision of more collaborative and local care. Hope it can be delivered. Perhaps do a summary also to make this more accessible?

I think there should be some mention of Joint Strategic Needs assessments focussing on a neurology JSNA. ICB's commission for population health and there are very few that are considering neurology as part of JSNA's. I think highlighting the need for this fits well with population approaches and at least then raises this at ICB level

We welcome the proposals outlined in the Specialised Neurology Service Specification and Annex A Minimum Service Levels documents to improve the integration of care and the ambitions of the service specification to address inequalities in access to specialised neurology services. To further enhance the Minimum Service Levels in Annex A, we believe there needs to be more specificity and guidance on multidisciplinary teams (MDTs) to help encourage more MDTs to form across the country.

4. Impact of Engagement

Following a comprehensive review of the feedback from stakeholder testing further action was taken where appropriate to update the service specification and the associated documentation i.e. EHIA. The comments received via stakeholder testing are appended to this document. The key changes to the document are detailed below:

- A clearly articulated, comprehensive model of care
- Requirements for specialised neurology services but also outlining the expectations of a system wide approach
- Includes reference to specialised services for Functional Neurological Conditions (FND) which were omitted in 2013 version.
- Includes reference to Complex Headache which were omitted in 2013 version.
- Greater clarity provided re: sub-specialty services in Annex 1
- References to pathways for pre-pregnancy and perinatal care
- Stronger interface and pathways between neurology and geriatric services

- Inclusion of transition and strong emphasis on joint working with paediatric services

5. How has feedback been considered?

Responses to engagement have been reviewed by the Specification Working Group and the Trauma PoC with some edits made to the service specification to improve clarity. The full detail of the feedback and changes made are included in appendix 1.

6. Has anything changed in the service specification as a result of the stakeholder testing and consultation?

Yes, edits were made to the service specification as a result of feedback received. The service specification change form is appended to this report.

7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?

No.

8. What are the next steps including how interested stakeholders will be kept informed of progress?

The service specification, change form and associated documents will be published as part of the full methods process. We also plan to hold another engagement session with patient groups / charities, working in partnership with the NHS England engagement team and the Neurological Alliance.